Working Together

A Guide to Collaborative Research in HIV Prevention

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Preface

This manual is a result of 15 years of research and experience and was created to encourage and support community collaborative research. Academic researchers at the Center for AIDS Prevention Studies (CAPS), AIDS Research Institute, University of California San Francisco, have been conducting research in collaboration with Community-Based Organization (CBO) partners since 1986. In 1991, the Technology and Information Exchange Core (TIE Core) at CAPS initiated a more structured, deliberate strategy for linking researchers and CBOs to conduct community-relevant research. Five CBOs were matched with 5 CAPS researchers and funded with small evaluation grants for two years. In 1994, Northern California Grantmakers (NCG) — AIDS Task Force and CAPS began a partnership which would continue for the next 6 years and fund 18 CBO/CAPS research projects in two collaborative consortia. The CAPS/NCG Collaborative Research Consortium Model has been evaluated and found effective, and subsequently been replicated with various modifications across California, and in New York and Chicago. Please see Appendix B for a detailed description of the CAPS/NCG Model.

After 8 years of conducting Collaborative Research Consortia, the TIE Core began to research the methods of collaboration in an effort to understand what elements made for successful collaborations. The Legacy Project looked at best practices for collaboration and capacity building among the 18 CAPS/NCG partnerships. The Collaborative Data Analysis Project (CDAP) identified and described models of effective collaboration during the data analysis process. Two outside evaluators, Harder & Company Community Research and Tom Backer & Associates, also looked at the effectiveness of the CAPS/NCG Collaborative Research Consortium Model.

This manual has been written and reviewed by both researchers and CBO staff. We would like to thank the following CBO partners for participating in the Collaborative Research Consortia and the research projects: AIDS Project of the East Bay; AIDS Resources, Information and Services of Santa Clara County (ARIS); Coalition of Immigrant & Refugee Rights & Services (CIRRS); East Bay Community Recovery Project; Face To Face/Sonoma County AIDS Network; La Clinica de la Raza-Fruitvale Health Project, Inc.; Larkin Street Youth Center; Centerforce, Health Programs Division; Marin AIDS Project; Mid-Peninsula YWCA; New Conservatory Theater Center; STOP AIDS Project; Tenderloin AIDS Resource Center (TARC); Tri-City Health Centers and Huckleberry Youth Programs (formerly Youth Advocates, Inc.). We would like to thank the following researcher partners for participating in the Collaborative Research Consortia and the research projects: Michael Acree, Diane Binson, Don Chambers, Katherine Haynes Sanstad, Kyung Hee Choi, Michael De Mayo, Rafael Diaz, Maria Ekstrand, Bonnie Faigeles, Ellen Goldstein, Cynthia Gomez, Olga Grinstead, Tom Hall, Gary Harper, Jay Paul, Kathleen Quirk, Fabio Sabogal, Ron Stall, Ariane van der Straten and Bill Woods. We would like also to thank the following funding partners from Northern California Grantmakers — AIDS Task Force for participating in the Collaborative Research Consortia: John Mortimer, Wendy Everett, Ruth Brousseau and Nancy Frank.

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Chapter 1

How to Use This Manual

Our hope is that this manual will inspire you to try collaborative research, provide you with information to make that a successful experience if you do try it and enhance any collaborations in which you are already engaged.

Chapter 1

A major goal for both researchers and CBO staff is to make a difference in people's lives by helping prevent new HIV infections. After 20 years, there is a large body of scientific research as well as front line experience about what works in HIV prevention. Collaboration uses both these resources to ensure that we're doing our best to achieve that goal.

TOP FIVE REASONS WHY YOU MIGHT HAVE PICKED UP THIS MANUAL

1. You have some questions about the effectiveness of your agency's programs. Or you have a question about a certain population and you'd like to know more. You know that the best way to get answers would be to link up with a researcher or CBO, and you'd like the process to be as inclusive and collaborative as possible.
2. You wrote in your grant proposal that you would work collaboratively with a researcher or CBO partner. Now the grant is funded and you need some suggestions about how to start.
3. Your local Health Department sent you this manual and you think this means they're going to expect you to collaborate with a researcher. You want some quick guidance.
4. Your local Community Planning Group (CPG) has announced that all funded projects must incorporate research into their design and evaluation.
5. You've been working in what is supposed to be a collaboration between researcher and CBO staff, but it's not going as well as you'd like.

Whatever the reason, in these pages you'll find a wealth of information and guidance drawn from research and years of experience with collaboration. In this manual we will discuss the process of collaborative research from conceptualizing a research question to analyzing data and disseminating research findings. Our hope is that this manual will inspire you to try collaborative research, provide you with information to make that a successful experience if you do try it and enhance any collaborations in which you are already engaged.

WHAT IS COLLABORATIVE RESEARCH?

For the purposes of this manual, *collaborative research* is research that is conceived, planned and conducted in collaboration between academic researchers and CBOs. It also includes data analysis and interpretation and dissemination of findings done in collaboration. Research may be defined as collaborative if a collaborative process was employed in any of these stages of research; the more stages in which collaboration can be accomplished, however, the more potential benefits accrue. Our perspective is that collaborative research often results in better programs and more relevant findings compared to cases when research

is conducted either by a researcher alone without community input or by an agency alone without the collaboration of a researcher.

The goal of collaborative research is to bring the experience, observations and skills of community service providers together with the technical expertise of researchers to produce meaningful community-based research questions which enhance research methods and modify and develop community programs.

Although our work has focused on the application of collaborative research to HIV prevention program evaluation, we hope that these principles will be useful to promote and guide collaboration in other areas as well. We also encourage those who are interested in learning more about collaborative research to seek out examples and lessons learned from other areas of public health including smoking cessation, violence prevention, family planning and breast cancer research.

KEY POINTS: COLLABORATIVE RESEARCH

These are the "golden rules" of conducting research collaboratively. Listed at the end of each chapter in this manual are key points for collaboration, and the lessons below will be repeated in many of them.

Get funding. Set appropriate expectations for research efforts and fund accordingly; budget adequate resources for the project.

Specify roles. Staff the research project appropriately and specify key roles for researchers, CBO staff, funders, and administrative support. A clear understanding of responsibility and task assignment is essential.

Be committed. Commitment from all parties of the collaboration is essential; buy-in from all levels of staff at both organizations is critical. Researchers should commit to active engagement with the CBO. The CBO should have a commitment to the research question.

Provide training. Acknowledge both CBO and academic researcher expertise and experience. Offer appropriate skills training when needed.

Meet regularly. Regular meetings between CBO staff and researcher staff are an effective way to foster peer support and sustain enthusiasm and commitment to the process.

Be flexible. Chaos happens. Be flexible and acknowledge real life at a CBO and the potential bureaucratic delays of conducting research.

Start early. The more time allowed for setting up a collaboration, the better prepared each party will be.

Case Study

THE STOP AIDS PROJECT'S COLLABORATION WITH CAPS

Dan Wohlfeiler (Education Director, 1990–98)

We at the STOP AIDS Project were particularly lucky to have access to academic researchers with a strong commitment to the community. While many academics represent an excellent example of a "hard to reach" population, Center for AIDS Prevention Studies (CAPS) researchers both studied and were members of our own community. It was simply a matter of calling them up and asking for their help.

We wanted to measure the impact of our interventions on our workshop participants. Over many bagel breakfasts with CAPS' Ron Stall and Maria Ekstrand, we developed a six-month follow-up questionnaire. We quickly learned that our own system lent itself well to sending out initial and even follow-up questionnaires, but getting those follow-up questionnaires back proved to be a real challenge — and took a lot of effort to integrate into our own program. While we didn't have a control group to be able to draw real conclusions, our own "reckoning day" showed us that we were moving participants in the right direction (much to our great relief). The data boosted our staff and volunteers' morale, and kept our own fundraiser very, very happy.

Later on, we were able to collaborate with CAPS and other researchers to see what our project's impact was on the community. We worked with the Young Men's Health Study, which surveyed a group of randomly-sampled men and gave them HIV tests each year. In their survey, we added a lot of questions about what their exposure to or involvement in the Project had been in order to find out if we had any impact on their seroconversions.

When we were writing our theoretical justification, our researcher said, "This year Social Learning Theory is what the funders are looking for." I told him that I could describe our project using one of any number of theories, from Social Learning Theory to the Health Belief Model to Stages of Change to theories of social support and community organizing, since in real life they all explained parts of our project.

Two men at a STOP AIDS safer sex educational meeting.

Our results were modest, and we didn't have the degree of impact we wanted. We did learn that we were reaching a very high percentage

of our population with our outreach, media, and group workshops. I wish I could tell you the final results — but like so many researchers, we have found that it's a lot easier to gather the data than to analyze them fully, write them up and publish them. We also proved that CBOs can, in fact, conduct outcome evaluation if they can partner with the right researchers.

Our Project had always recruited men off the street into workshops with other men who didn't know one another. Based on social support theories — which suggest that if people have explicit practical and emotional support for healthy behavior they're less likely to take risks — I wanted to try recruiting whole social groups, from the gay chorus and gay softball league to groups of friends, for our workshops. I hoped that instead of sending men out from the workshops back into the community where they may never run into each other, these social groups would allow the explicit conversations which started in the workshops to continue.

Recruitment turned out to be a much greater challenge than we ever imagined — and much to my own disappointment, we ended up abandoning the project halfway through our funded collaboration with CAPS. We did get some great qualitative information about how men in groups did and did not ask one another about their risk behavior, and how they used groups as a way to get a life *outside* of AIDS. So all was not lost. Could more formative evaluation have helped us understand better how hard this would be to carry out? Probably. And despite the fact that I'm no longer at STOP AIDS, the funding for that intervention has long-since dried up, and the staff I asked to implement swear they'll never attempt it again, I still remain convinced that groups offer a real advantage for HIV prevention. Although it goes against my belief that if it didn't work, don't repeat it, I still have faith that a community member and researcher will figure out how to improve our design and see if it really can make a difference.

Chapter 2

Why Collaborate?

Researchers and CBO staff working collaboratively can enhance the strengths of both fields, and enrich the research process by bringing various skills and knowledge together.

Chapter 2

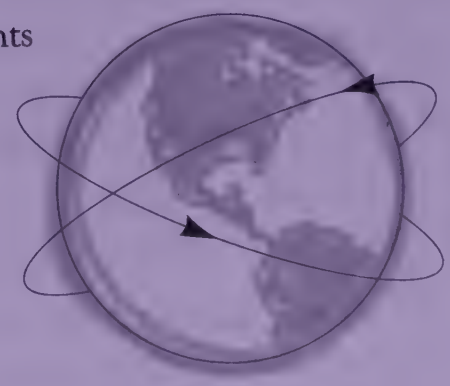
In a perfect world, academic researchers, CBO staff, health departments, and AIDS activists would all work together. We would recognize the experience and wisdom that each had to offer in our collective efforts to stop HIV from spreading. We would interact regularly, share our knowledge and expertise, and use all the lessons learned to develop better prevention programs.

Unfortunately, when conducting research, designing programs or developing theories, most CBO staff and researchers do not automatically think of turning to each other for input. This is understandable, given that collaboration is not something either partner is necessarily trained to do or has the funding for. There is also a long history of mistrust and stereotyping from both sides. One way to understand the disconnect between CBOs who conduct HIV prevention programs and scientists who conduct HIV prevention research is to think of these as two separate cultures. The interactions between the two represent the equivalent of a cross-cultural experience. As such, we can expect misunderstanding and culture shock between the two worlds. But, as in all cross-cultural communications, we can also expect learning, expanded perspectives, and excitement when we meet successfully.

COLLABORATION AS A CROSS-CULTURAL EXPERIENCE

The worlds of research and CBO program delivery are often separate, with each having its own sense of time, incentives, language, resources and authorities, among other things.

- **Time.** An immediate client crisis that needs to be handled *right now* vs. a five-year research grant and submitting findings to a journal that won't publish an article for 6–12 months
- **Incentives.** Units of service, number of unduplicated clients vs. numbers of grants and publications
- **Jargon and language.** CTRPN and HE/RR vs. random sample and statistical significance
- **Resources.** Peer networks, trainings vs. research, administrative support, Internet, library
- **Authorities.** Clients, funders, departments of health, experience, colleagues vs. scientific literature



When people who work with and identify with one of these cultures interact with someone from the other, it's not hard to see why the result can be often unsatisfying or confusing.

OVERCOMING CULTURAL BARRIERS

If we consider research and program delivery as two different cultures, we realize that we cannot automatically assume that we understand the meaning of behavior or how norms in the other culture operate.

It is always important to ask questions

If a researcher asks for CBO feedback on an instrument by next week and is told that the CBO staff can't get to it, she shouldn't assume that the CBO staff are indifferent or sending the message that the research isn't a priority. Perhaps the CBO is having a site visit or one of the key staff members just went out on disability. Or perhaps the computer system is down and they don't have the budget to fix it.

If a CBO proposes a research question for joint study and the researcher is unenthusiastic, it may be because the resources can't answer a question of that complexity or because a paper just came out in a journal that answers the same question. From both sides, it's important to ask for clarification.

If the researcher wants to review and modify codes on a questionnaire or a CBO staff member wants to revise the same questionnaire for cultural appropriateness, the common goal is to develop a questionnaire that will best give voice to community experiences. If a researcher focuses on publishing in an academic journal and a CBO program manager spends time on a presentation to the local Community Planning Group, both are engaged in efforts to disseminate their findings. They just have different resources and expectations about the accepted or best way to do it. Neither one or the other is better; combining both may be the best solution.

Cross-cultural differences do impact collaborative relationships, but in real life, the line between researcher and CBO staff is often blurred. CBOs often have staff with graduate degrees and research skills — people who look at the intake forms, the client satisfaction surveys, and the workshop evaluations as data, feeding the information back to the program for further development. Also, researchers are members of the HIV-infected and affected community. For example, after his input was dismissed at a Community Planning Meeting because he was presenting epidemiological data, an HIV+ researcher asked, "How many of my friends do I need to bury, and how sick do I need to be before I am considered part of "The Community?" The bottom line is that we are all working for the same goal, all committing our time and skills to ending the epidemic. We can do it better when we work together.

DISADVANTAGES OF WORKING SEPARATELY

Researchers and CBOs can and do work separately on research projects. Researchers who want to design or evaluate an HIV prevention intervention could (and often do) develop the intervention based on theoretical constructs, recruit participants on their own and conduct the intervention in venues created specifically for that research study. Researchers could (and often do) collect, enter, analyze and interpret data and disseminate their findings without community input. There are several disadvantages to this approach:

- Researchers often have the money and time to design interventions that are so

comprehensive and resource-intensive that they are impossible to replicate in a community setting.

- Researcher-driven studies may be based on what is printed in scientific journals rather than what is most currently needed among clients at risk for HIV.
- Research findings may be interpreted based on the numeric data or one-time, focused interviews, with little knowledge of the daily life of clients surveyed.

On the other side, CBO staff who want to design or evaluate an HIV prevention program could (and often do) develop the intervention based on what they've seen and heard from their clients, offer the intervention to the "usual suspects" in the community and design or adapt pre- and post-test surveys for evaluation. In fact, CBO staff have been pushed in this direction as more and more funders are demanding the development and completion of a program evaluation plan. For CBOs, working alone has its disadvantages:

- Without consulting the HIV prevention research literature, CBO staff may duplicate past failed efforts. Certain program components may have been proven unsuccessful, while others have proven to be highly effective.
- CBO staff may be conducting research, especially evaluation research, only to fulfill requirements from the funder. Often CBO staff don't have the time or inclination to step back and look at the big picture, or to make sure the research they're conducting helps the agency as well as the funder.
- CBO staff may rely on anecdotal measures of success (e.g., clients really like the program). Without evaluation research, it is often difficult to know if programs actually help change behaviors or attitudes of clients.

ADVANTAGES OF COLLABORATION

- Programs designed or evaluated in collaboration with CBOs are already known to be feasible in community settings.
- Collaborating with a CBO ensures that research actually reflects the current needs of affected communities.
- CBO staff bring valuable insights into why clients may be responding in a certain way or making certain choices, which results in richer and more useful data analysis and interpretation.
- After 20 years of scientific research on HIV/AIDS there is a large body of theoretical and applied knowledge about what works in HIV prevention. Researchers are often well versed in this literature and can assist CBO staff in adapting programs which have already been tested and proven effective.
- Researchers have the technical expertise to hone a general question into a specific and well-defined research question and to develop a research plan using the methods best suited to answer that question.

Researchers and CBO staff working collaboratively can enhance the strengths of both fields, and enrich the research process by bringing various skills and knowledge together. In addition, working collaboratively can build capacity for CBO staff and researchers:

- Increase research skills of CBO staff through trainings. Increase skills of researcher for translating theory into programs.
- Help secure funds (researcher can fund CBOs through grants, researchers can get money from Community Planning Groups, etc.).
- Both parties will learn more about what makes an effective program.
- Researchers can gain access to unique at-risk populations.
- Both gain access to alternate sources of information and dissemination: CBOs to academic journals, researchers to newsletters and outreach workers.

FIELD NOTES

A CBO providing services to incarcerated men and their families knew they were doing innovative work but did not have the technical expertise to conduct evaluation. An academic researcher knew that the incarcerated were an important population to study but knew there were major obstacles to getting access to prisons and jails.

The CBO director approached the researcher to provide technical assistance in evaluating their HIV prevention programs for incarcerated men. Each partner got what they wanted: evaluation expertise and an inroad to incarcerated populations.

This collaboration has continued now for more than 8 years and has included the evaluation of five different programs, as well as the collaborative development of four interventions for inmates and their partners. Programs based on these interventions are now being implemented throughout the California Department of Corrections.

IS COLLABORATION FOR YOU?

Collaboration is not for everyone. Neither is a collaborative relationship necessary for every research project. There are times when a researcher might use a Community Advisory Board to solicit input and advice from CBO staff and community members about their project. CBO staff may prefer to hire a researcher consultant to conduct a needs assessment for their client population. As you'll see in the next chapters, research collaboration takes time and commitment. While we believe that collaborations can improve both research and services, not everyone has the time and resources to engage in collaborative research.

There are also several different forms of collaboration. Collaborative relationships can occur between CBO staff and researchers alone, between both partners with an outside facilitator, and as part of a consortium of other CBO/researcher teams. All of these can work and be useful, but it's up to the partners to decide how they might work best. It should go without saying that in each case, respect and admiration for each other's strengths is first and foremost. In all of these cases, researchers and CBO staff can work together on defining the research

question, developing the surveys, collecting the data, analyzing the data and disseminating the findings.

When CBO staff and researchers collaborate on their own, there is often a lead agency, and this agency is most likely the one that controls the funding. In this case, one agency might make overall decisions about what they want to study and the timeline and desired outcomes. Collaboration still occurs during the process of research, and the lead agency needs to be flexible and agree to compromise when needed.

CBO staff and researchers can also work with a facilitator for their collaboration. A facilitator can work with a collaborative relationship from the beginning, overseeing and managing the collaboration, or can be called in at different times to help overcome obstacles. The facilitator can be a mediator and a trainer, helping form an even playing field between researcher and CBO staff, and providing ground rules as well as flexibility.

Sometimes collaborative research is conducted with a consortium, where one lead agency oversees and manages several collaborative projects in a certain geographic area or in a certain field. This model is often used in health department or university settings where several programs may be funded from one source. Consortia usually have a lead facilitator trained in collaboration who convenes regularly scheduled meetings of all the agencies involved. In this model, collaborative projects can learn from each other and help problem solve as a group. Please see *Appendix B* for a description of the evaluated CAPS/NCG Collaborative Research Consortium Model.

KEY POINTS: WHY COLLABORATE?

- Collaborative research is a cross-cultural experience.
- Ask questions. Don't assume you know what the other side is thinking.
- There are advantages to collaborating for both researchers and CBO staff.
- Collaborative research isn't for everyone or every situation.

Chapter 3

Starting a Collaboration

Building a good collaborative relationship at the beginning will smooth the way for better research and better services.

Chapter 3

Collaborations, like any relationship, require effort to get off the ground. Consider starting a collaborative research project with the same care used to start a new romantic relationship, find a caregiver for a child or choose a healthcare provider. Because collaborations between researchers and CBO staff are cross-cultural relationships, they require even more care and nurturing. This chapter is a step-by-step guide to conducting healthy collaborative research partnerships between researchers and CBO staff. We'll begin as the collaboration starts, then move into how to maintain the relationship.

GETTING THE RIGHT FIT

You have the time, commitment and desire to collaborate on a research project. Now, how do you find a partner? This is the beginning of a new relationship, and it's important to start off right. Please see *Appendix* C for resources for finding collaborative research partners.

Once you have potential names, call them and set up a time for an interview or "first date." Ask for a resume and references and then actually call the references. Some things to look for and ask about are:

- **A history of conducting research.** What kind of research has been happening in the organization? Does your potential partner know basically what to expect from a research project?
- **A history of collaboration.** Has the person or organization collaborated with others before? How did the experience go?
- **Knowledge/experience with the population.** How long have they been working in this area? Are they aware of the basic needs and history of the population?
- **Specific requirements of the project.** Does the researcher or agency staff have the specific skills needed for this project? For example, does the researcher need to speak/understand Spanish? Does the CBO need to have access to African-American men who have sex with men?

If at all possible, interview several possible partners to be able to compare strengths and weaknesses. It may be the case that there is only one CBO or only one researcher working in HIV prevention in your area. Even if you don't have the luxury of choosing between several candidates, it is still important to have an initial interview and ask questions. This lets the partner know that collaboration will be taken seriously, and allows time to get to know a bit more about each other's background. It is also an opportunity to educate potential partners about what to expect.

ARE YOU COMMITTED?

Once both the CBO staff and researcher are clear about their goals for collaborating on a research project, it's time to check that the commitment to work through this process is there. The primary areas to check are time, support and funding.

- **Time.** Does each partner's job allow for the work required in collaborative research? Assume a research project will take at least 10–20% of your time for one or two years (time spent each month will vary depending on the stage of research).
- **Support.** Does each partner's agency and direct supervisor support a research collaboration? Are the support staff (statistician, outreach workers, project assistants) aware of the project and on board?
- **Funding.** Is there money to cover all of the above? You don't want funding to run out halfway through a project.

BUILD A RELATIONSHIP

Building a good collaborative relationship at the beginning will smooth the way for better research and better services. Researchers and CBO staff should hold an initial meeting and make an effort to understand each other's skills, commitments, expertise and culture. Did the CBO program manager major in biochemistry and then decide he wanted to work directly with people and not in a lab? Did the researcher start off in a neighborhood health clinic and then go back to school to learn about research? How did each participant come to their current work in HIV?

Develop trust by spending time together, sharing plans and aspirations and listening openly to alternative points of view. Establishing a foundation of trust is one of the most important aspects of successful collaborations. Trust can help overcome many barriers. When trust is present in a relationship, communication is clearer, relationships flourish and partners are more open to input from the other. Without trust, communication is delayed or reluctant, expertise and credibility are doubted and both partners resist learning and growing.

Researchers should visit the CBO to see programs in action and to develop a level of comfort with the culture of the community. Researchers should also note what resources the agency has such as computers, software, e-mail and a fax machine. If the research project will take place off-site, the researcher should visit the intervention site as well. Conversely, the CBO staff should visit the research offices. Researchers might have resources that could be made available to CBO staff, such as a university library, free access to the Internet or copy machines.

MAINTAINING A COLLABORATION

All relationships, especially cross-cultural ones, hit bumps along the way. Even CBO staff and researchers who are experienced collaborators and have followed all the best practices outlined so far in this manual will run up against problems. Here are some ideas to prevent and overcome these common barriers.

Regular Meetings

It is vital to set up regular meetings throughout the collaboration. These meetings are important not only to track the progress of the research, but to build trust, get to know each other and maintain relationships.

- Set a specified time — e.g., Monday afternoons at 2:00 — and try not to change it unless it is absolutely necessary.
- Researchers should meet at the CBO in order to get a sense of the organization and the programs.
- Having food at meetings is a good idea, whether people bring their lunches or each takes turns bringing bagels or donuts.
- Depending on the topic of each meeting, there should be someone designated to take notes. At the end of each meeting, this person should go over who does what and the timelines so that everyone agrees with their tasks.
- Make sure to schedule enough time so that everyone who needs to has time to speak and get their questions answered.
- Meetings should occur frequently (once a week) at the beginning of the collaboration and other times of intense work (such as data analysis), but can slow down when needed.
- Don't make assumptions about how much each person knows and understands. Even if a researcher has seen the intervention and trained interviewers, he may still need reminding about the details of the intervention.

FIELD NOTES

A researcher and CBO targeting underserved communities of color collaborated to look at family histories of injection drug users. Scheduling meetings with research and CBO staff was difficult due to the hectic lives and competing interests of everyone involved. Also, outreach workers had difficulty concentrating on the research project when meeting because they were thinking about their other obligations.

They decided that the best time to get everyone together was early in the morning, so the researcher went to the agency at 8 a.m. every Wednesday, where she met with the project director and outreach workers. Each meeting began with a personal check-in, where people could talk about what was going on in their lives. This helped diffuse tension, build trust and allowed everyone to focus on the task at hand during the rest of the meeting.

Involving the researcher, CBO staff and people in all stages of drug recovery ensured the collaboration benefited from lots of expertise in lots of different areas such as substance abuse, community and research.

Throughout the collaboration it is important to repeat and possibly redefine roles and responsibilities. For example, both partners might have decided at the beginning of the project that the researcher or someone on her staff would enter the data once collected. But what if one of the outreach workers who administered the questionnaire got excited by the process and wanted to join in the data entry? Allowing roles to expand and change maximizes the learning experience of everyone involved.

Training

As both researchers and CBO staff are entering a domain that may be new to them, orienta-

tion and training are key. While it is fairly obvious that this should occur at the beginning of the collaboration, additional training may be needed throughout the relationship. Specialized training may be called for later in the collaboration on topics such as interviewing techniques, confidentiality or data analysis. Often, this is carried out by the researcher; however, the trainer should be familiar with the CBO environment and respectful of the different strengths and experiences between CBO staff and researchers.

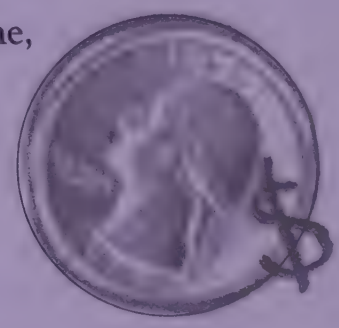
Researchers should give CBO staff an introduction to theory and practice of research and evaluation. Be sure to set aside time for questions and small group interactions. CBO staff should give researchers an introduction to program delivery issues such as funding cycles for services, Community Planning and its impact on programs, population needs and nuances, service delivery practices, etc.

Training will also be needed as staff turnover occurs and new staff are hired. Both researcher and CBO staff need to commit to training new staff as they arrive to ensure that the research skills of the agency do not leave with the employee. Having support from the CBO and, if possible, from a facilitator or other research teams in a consortium, can help smooth the transition between staff. It is a good idea to have a booster training midway through the collaborative project. If disagreements or misunderstandings occur, if research results aren't matching what the CBO staff or researcher was hoping for, or if the research team is stymied by any data collected, it might be a good time to go over what has been learned and make sure everyone is looking at the situation from the same knowledge base.

Support

Adequate funding and support in all levels of the CBO and the research institution are essential in maintaining an effective collaboration.

Monetary support. Research is routinely conducted at academic research centers — that's what researchers are paid to do. But many CBOs do not routinely conduct research, and most CBO staff are not paid to do so. Therefore it is important to budget appropriately.



- All CBO staff involved in the collaboration should be paid for their time, including time attending meetings and trainings.
- For CBOs, budgets should include funds for the intervention (if one is being designed or tested), the evaluation and for dissemination of study findings.
- For researchers, budgets should include meeting times, training and dissemination.
- Both should recognize that collaborations are time-intensive and may take longer or require more personnel time than working alone.
- Both should commit to multi-year funding to ensure a smooth process and continuity.
- If at all possible, include funders in the collaboration process. Invite funders to collaboration meetings and provide regular feedback on the progress.

CBO support. Again, research is not a part of most CBOs' scope of work. In order to

ensure support during the collaboration and to build capacity for research in the CBO after the collaboration, a wide array of CBO staff must be involved. The agency as a whole should be receptive to and aware of the value of research. Ensuring buy-in from various parts of the agency will also help when staff turnover occurs. Encourage buy-in by:

- Inviting Executive Directors, department heads, front line workers and administrative staff to meetings from time to time.
- Reporting back to the rest of the agency at timely intervals on the progress of the collaborative research.
- Including the agency in dissemination plans.
- Focusing on how the research can help the agency learn about its clients or programs.

Collaboration support. At some point all relationships hit rocky areas, and collaborations are no exception. When collaborations get stuck, it is recommended that a neutral party be brought in to offer support and facilitation. For researchers and CBO staff working without a facilitator or as part of consortia, this is especially important. In the facilitated or consortia models of collaboration, a person is already designated to support the relationship. This person can help clarify roles and responsibilities, open lines of communication and mediate any disputes.

Working in the consortia model of collaboration also provides support to CBOs and researchers by allowing for peer support. Meeting with others involved in collaborations gives CBO staff or researchers a chance to compare their processes and brainstorm solutions. Just as peer support and peer education are powerful educational tools in promoting healthy behaviors, peer support empowers members of the collaboration consortia to learn new skills.

Flexibility

Chaos happens. Working in a collaboration does not offer protection from chaos, but rather doubles the chances of encountering it. Researchers and CBO staff need to be especially flexible in order to survive the bumps along the road. Flexibility is needed not only in interactions within the collaboration, but within the research project itself. Research questions may need to be altered, surveys rewritten or data analysis re-reviewed to accommodate real life. Researchers and CBO staff need to keep an open mind:

- Ensure that all participants are committed to the services being offered, to the evaluation project and to the consortium.
- Understand that CBO staff and researchers have different timelines. They also have different problem-solving techniques.
- Collaboration can be a learning experience for all: CBOs learn about the process and skills of evaluation and researchers learn about the needs of clients in a service agency.
- Be prepared to compromise and try new approaches. Questionnaires may end up asking different questions than a researcher expects; interventions may have different components than a CBO project director expects.
- Keep your mind open to alternative viewpoints and solutions.

- Build a back-up research question into the research design.
- Keep a close watch on the progress of the collaborative research and make sure timelines are set and adhered to.

It's important to keep reminding yourself that the reason for engaging in a collaboration is not to make more work for yourself (although it may sometimes seem that way). The reason to engage in collaborative research is to improve the services and research we conduct so that together we are more likely to help slow the HIV epidemic. Following these best practices can help the collaborative research project flow smoothly and ensure that each partner has a chance to learn and to improve their work.

The next chapters describe the nuts and bolts of conducting research collaboratively: defining the scope of work, collecting data and conducting data analysis.

KEY POINTS: STARTING A COLLABORATION

In order to get the best results, these conditions should be in place for successful research collaboration:

Goal. The goal of collaborative research is not simply to collaborate, but to conduct better research to improve services to help slow the spread of HIV. This common goal can help keep collaborations on track.

Commitment. There needs to be a strong desire within your organization to collaborate and conduct research. Ideally, there is buy-in from all levels of staff.

Desire to Learn. Each partner should be interested in learning from the other and the process of collaboration. Each should acknowledge the expertise and experience of the other and be willing to admit that there are things they do not know.

Time. Collaboration is labor-intensive and everyone involved needs to be prepared to devote the time necessary to make collaboration work. There is no quick and easy way to collaborate.

Support. Each organization needs to have the capacity to take on a collaborative research project and provide the support it will need in terms of training, meeting and administrative and technical support.

Funding. Collaborating will likely require additional funds for each organization. Make sure that time and effort are written into the grant or covered by current salaries.

Flexibility. Research and CBOs have their own bureaucracies and are affected by a myriad of outside influences such as policy changes or natural disasters. Partners need to expect challenges and be willing to apply resources to work them through.

Adapted from: *Beyond Our Borders: A Guide to Twinning for HIV/AIDS Organizations*.

Case Study

AGAINST ALL ODDS: CONDUCTING RESEARCH IN A CBO

by Drew Feraios

As the deputy director of a grassroots CBO, I began a collaboration with CAPS researchers not so much for evaluation expertise, but more as part of our ongoing struggle to fund our programs.

During the summer of 1996, I was working at AIDS Project East Bay (APEB), an agency that provides HIV prevention and services programs in one of the more underserved communities found in the Bay Area. We were still reeling from the election of the Republican majority and the subsequent passage of Welfare Reform. So when we received an RFP from Northern California Grantmakers (NCG) for an evaluation project that would pair our agency with a CAPS scientist, we naturally applied for it to help ensure the agency's survival.

We had just lost funding for our prevention program targeting substance users, so this new RFP provided us with the means to retain an exceptional employee and a needed program. What the program was mattered far less than the fact that a new source of funding might be in the offing.

The first culture clash between our agency and the CAPS researchers came when we tried to describe the program and how we wanted to evaluate it. After several meetings in which we tried to finalize a research question and a methodology, we came to the consensus that our program was something we pieced together as best we could from as many funding sources as we could find to do something we knew had to be done: provide prevention services to substance users in Oakland. Once we found the language to explain how the program worked, CAPS scientists helped us develop an evaluation methodology in harmony with the grassroots nature of the program.

The second culture clash had to do with the fact that CAPS staff relied upon e-mail, voicemail and a computer network. We at APEB were severely limited by our lack of '90s technologies. Even when we tried to work from computer disks, our version of Word could not read documents from CAPS! We found that the best way to keep the channels of communication open was to meet once a week at 8:00 AM; these meetings continued long after funding for the project dried up.

That we succeeded at all in completing the evaluation is a testament to those of us that made up our team: Diane Binson and Bonnie Faigeles at CAPS; myself, Oliver Saunders, Marvin Williams, and Lynn Mayberry from APEB. More than a year after the funding

ended, we still meet and are close to developing manuscripts from rich qualitative data about the lives of substance users in Oakland.

For me, the result of our collaboration was twofold: 1) We finally had data about the magnitude of the social problems faced by our clients to share with funders and the public, and 2) I realized I could not continue working in services, and that research offered me a different path to address the same issues. At the final meeting of the CAPS/NCG Collaborative Research Consortium, I presented the data from our project by painting a picture of the lives of those we had studied. The room was silent and engaged as I described sexual and physical abuse and violence, parental alcoholism, prostitution, bouts of homelessness, along with stories of hope from substance abusers that had forged new healthy lives for themselves. At the very end, a woman in the audience revealed herself to be one of the subjects in the study, and with tears in her eyes, she told me that our team had "told it like it is." Nothing in all my years at APEB had so moved me. After the project was over, I was hired by the Center for Health Improvement and Prevention Studies (CHIPS) to be the project director of a federally funded study. Once I got to see just how much of the work we do in grassroots nonprofits is simply to make up for our lack of resources, I just couldn't do it anymore.

Funders often prevent CBOs from developing the infrastructure necessary to increase their productivity by offering progressively smaller funding units and progressively more intense restrictions on administration. This also increases the burnout rate among CBO employees, which reduces an agency's ability to serve its clients with their myriad concerns. The CAPS/NCG collaboration and my work at UCSF provided me with the hope of illustrating these community concerns and offering ways to ameliorate them. Today we at CHIPS are preparing to hit the field with an innovative study looking at smoking, drinking, HIV and drug risk behaviors among primary care patients in the Bay Area. After more than a year of working at UCSF, I continue to find hope that research may guide policy decisions that help bring about social change.

Chapter 4

Developing a Research Question

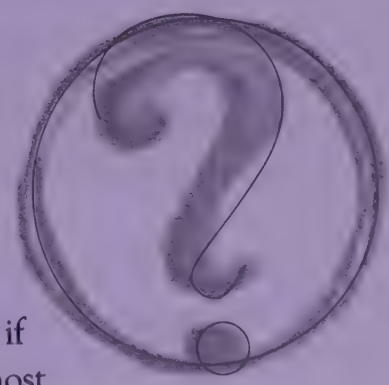
The key criterion of a good research question is: do you care about the answer? Do you believe that the answers to the research question will help you think about your work in a new way or provide a critical piece of information?

Chapter 4

One of the first tasks in deciding the goal of the collaborative research project is determining the research question: what do we want to know about the population we work with, or the services we provide? The key criterion of a good research question is: do you care about the answer? Do you believe that the answers to the research question will help you think about your work in a new way or provide a critical piece of information? Each collaborator brings his own expertise, and all of it will be useful in defining the research question. Generally, the CBO brings information about the program or services being studied and the daily realities of the target population, and the researcher brings expertise in evaluation and research procedures. Of course, some collaborators have overlapping experiences. Some CBO staff have been doing research for a long time, and some researchers are as familiar as the providers with a local target population. Being open to all the expertise among the collaborators will serve the goal of defining an answerable research question and developing good procedures for data collection.

While identifying a research question, it is important to determine whether or not it can be answered. Many times an initial research question cannot be answered because:

- There is not enough time or resources to carry out the research needed to address the research question.
- The question is more complicated than initially thought.
- It is not clear how to collect information that would answer the question.
- The question is not specific enough.



In these cases, the research question has to be restated or redefined. For example, it is reasonable that a CBO would want to know if their prevention program works — this is "outcome" research. But most programs can't assess a sufficient number of clients in a short enough period of time to be able to answer the question, "Does our program reduce HIV infections?" Nevertheless, there are plenty of other research questions about the program that are worth pursuing that can be answered. For example, instead of asking about outcome, it might be good to start out by asking if the program addresses the needs of the population it's meant to serve, or if staff are implementing the program as it was intended to be done — these would be examples of "process" research.

Collaborators should be flexible and prepared for changes to the research question. Having a backup question, or a secondary research question, is also valuable, since sometimes the primary question cannot be answered definitively.

FORMULATING A RESEARCH QUESTION

Here is a step-by-step example of how one CBO and researcher team came up with a specific and manageable research question that got to the heart of what they wanted to know.

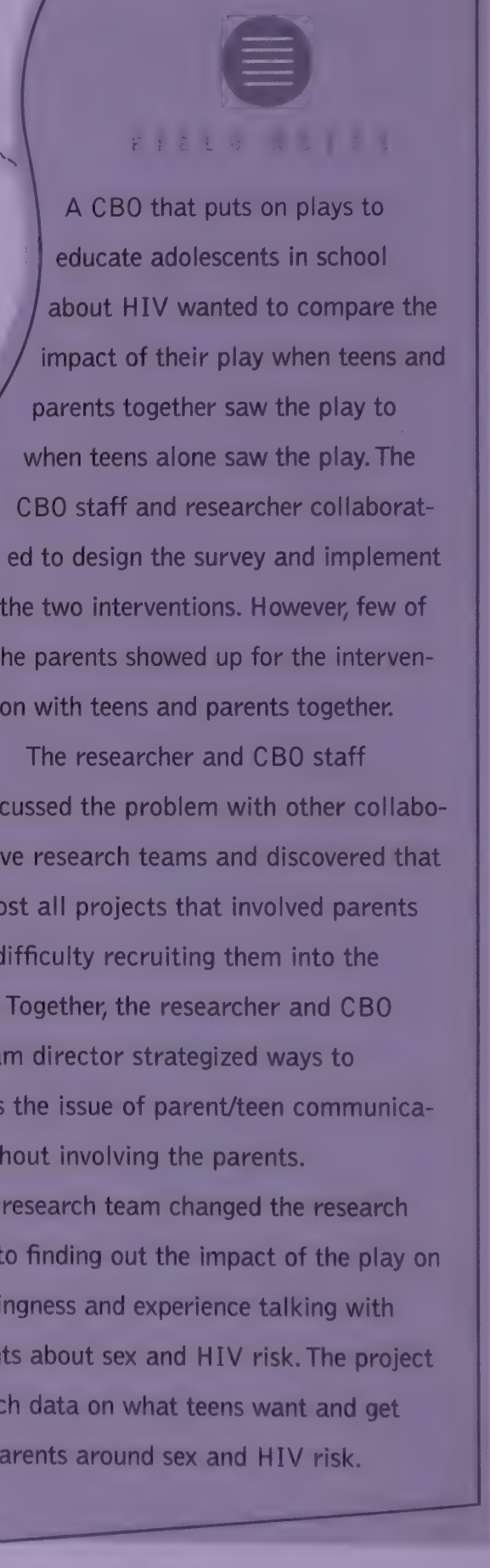
The program manager of a CBO providing drug abuse treatment was concerned that her agency's clients weren't getting HIV antibody tested, despite the fact that they were at considerable risk of HIV infection and that if they found out that they were HIV+, they could access early intervention services. The first question was:

Why don't our clients get HIV tested so those who are HIV+ can start early intervention treatments for HIV?

At the first project meeting, the program manager, researcher and several case managers discussed the research question. The researcher asked about the CBO's clients and wondered if they really wanted to know about all the clients or a particular subset. The case managers agreed that there were a number of reasons why certain clients had been unable or unwilling to be tested. One of the case managers noted that barriers were different among persons who believed they might be HIV+ as compared with those who believed they were HIV-, and that drug users who believed they were HIV+ were more willing to reach out for help. They all agreed to focus on clients who believed they might be HIV+. The research question then changed to:

Among clients who believe they are HIV+, what are the barriers to getting tested and to subsequently obtaining early intervention treatment?

The researcher noted that it might not be easy to differentiate between clients who think they are HIV+ and those who don't, which would make recruitment difficult. He suggested that they try to recruit all injection drug user clients who had not tested for HIV, and that in the analysis they could look for any differences between those who thought they were HIV+ vs. those who thought they were HIV-. A case manager



FIELD NOTES

A CBO that puts on plays to educate adolescents in school about HIV wanted to compare the impact of their play when teens and parents together saw the play to when teens alone saw the play. The CBO staff and researcher collaborated to design the survey and implement the two interventions. However, few of the parents showed up for the intervention with teens and parents together.

The researcher and CBO staff discussed the problem with other collaborative research teams and discovered that almost all projects that involved parents had difficulty recruiting them into the study. Together, the researcher and CBO program director strategized ways to address the issue of parent/teen communication without involving the parents.

The research team changed the research question to finding out the impact of the play on teens' willingness and experience talking with their parents about sex and HIV risk. The project collected rich data on what teens want and get from their parents around sex and HIV risk.

said that in his experience, barriers to HIV testing were very different for men than for women, that women who inject heroin were less likely to seek out services of any kind, and that more women seemed to be seroconverting than men. The program manager added that their clients were mostly male and she wanted to find out more about their female clients, even if they were harder to access. A case manager added that using incentives and offering child care might encourage women to participate. The researcher suggested they over-sample for women, that is, recruit equal numbers of women as men even though most of the clients were men.

One of the case managers brought up the topic of early intervention, and how the project would address that. The researcher noted that previous research had identified a relationship between HIV testing behavior and belief in/access to early intervention. The case manager concurred that in his experience, clients who knew about early intervention or used medical services were more likely to test. Therefore, the group decided to include questions about belief in early intervention and access to medical care in the questionnaire. The researcher suggested that instead of making that the research question, they should have a broad-based question and then look for differences or patterns in the analysis phase. The research question was finalized as:

What factors are associated with in-treatment injection drug users' decisions not to test for HIV?

Note that the conversation about the research question had implications for sample size and selection, data analysis, survey design, survey questions (topic areas) as well as the actual research question. Deciding upon a research question often overlaps the steps that follow such as deciding on recruitment strategies and designing survey instruments or interview guides. The next chapter will outline how to collaboratively begin the process of data collection and move into data analysis to get answers to the research question that will help strengthen programs and services.

KEY POINTS: DEVELOPING A RESEARCH QUESTION

- The mark of a good research question is that you care about the findings.
- Have a backup or secondary research question built into the research project from the beginning.
- Take time to discuss and hone the research ideas into the right research question.
- Make sure that both the researcher and CBO staff are committed to the research question.

Chapter 5

Collaborative Data Collection and Analysis

Working together through the various steps to develop and implement data collection and analysis procedures will result in better procedures that deliver more accurate data.

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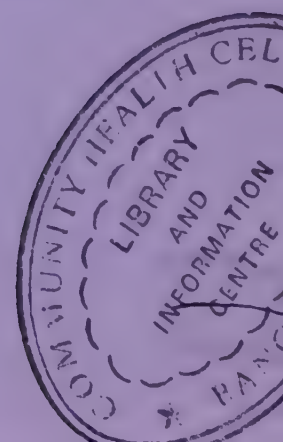


Chapter 5

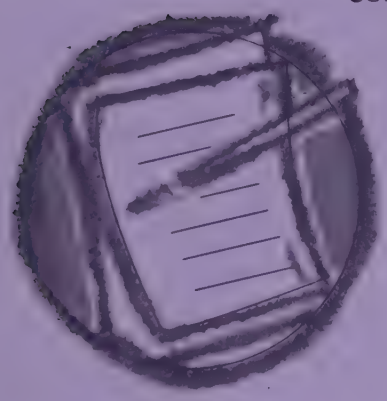
The last chapter showed how defining the research question in a collaborative manner can also help guide the data collection and analysis phases of the research project. Research progresses in phases: developing the research question, designing the surveys or other instruments, collecting data, cleaning data and entering data, then analyzing and interpreting the findings. Because all these phases of research are connected and overlapping, collaboration is necessary at each stage to ensure the best outcome and the ability to collaborate in future stages.

WHAT ARE DATA?

Data are all the answers gathered during the research process. Most commonly data are in the form of text or numbers, such as answers to interview questions, scales from 1–5, numbers of partners in the last 6 weeks, etc. There are also different levels of data you can collect, such as data on individuals, groups, organizations and communities. Data can be qualitative, that is, in narrative or text form, for example, information collected from focus groups or in-depth interviews. Data can also be quantitative, that is, numerical, in the form of numbers, for example, survey data and data from epidemiological reports.

HOW ARE DATA COLLECTED?

Data can be collected through surveys, interviews, observations, focus groups, forms, reports and materials that were constructed for other purposes, such as client intake forms. The research question will dictate the kinds of data needed and the ways in which it is to be collected. Deciding how to do it depends on the research question and how much is already known about the population. Procedures for data collection must be developed in detail and require the commitment of all the collaborators. Among the details to be defined are who will do what and how the procedures will be carried out from collecting the data to having it ready for analysis. Examples of tasks to be defined are: deciding what kind of data is most appropriate for answering the research question, constructing the interview or survey questions, typing and copying the survey, recruiting participants, getting food or incentives for focus groups, conducting interviews, entering data into the computer, reading through transcripts, transcribing tapes, etc.



WHAT IS THE PROCESS FOR COLLECTING AND ANALYZING DATA?

Data collection and analysis begins with conceiving the research question. The type of analysis conducted is linked to the type of data collected, which in turn is determined by the research question. The collected data may be qualitative, quantitative or a combination of both. The next section is a guide to the different phases of the research. (Please see *Appendix D* for a glossary of research terms.) The example of the research project studying drug users who do not test for HIV (described in the previous chapter, pg. 28) will be used to illustrate each step.

Data Collection Instruments

Once the research question is decided, the next step is to decide how to collect the information needed to answer that question. This can include writing detailed questionnaires, outlining focus group questions, designing interview guides or searching for existing archival data. Generally, the researcher provides guidance on design of instruments to make them compatible for analysis, and the CBO staff provides guidance on content and wording of questions. If a project decides to use questionnaires for gathering quantitative data, this phase of the research may take quite a while, as making sure the correct questions are asked is key. If the project will be collecting qualitative data, this phase may be shorter, with the bulk of the work coming at the data analysis phase of the project.

> *In our example, the research team wanted in-depth interviews with clients who had not tested for HIV. Because they wanted to do comparisons between men and women, and those who believed they were HIV+ and HIV-, they wanted to design a quantitative survey. At the end of the survey, they wanted to include more open-ended interview questions to allow clients to talk about their experience with HIV and issues in their lives that affect health seeking behaviors. The team spent a long time designing the questions for the quantitative survey, as CBO case managers wanted to make sure a wide variety of questions were asked in language that their clients would understand, such as history of violence and abuse, work experience, housing status, relationship with partner and drug use with partners.*

Once the instruments are designed, they should be pilot tested. This may entail holding a focus group of potential clients to discuss the questions and issues addressed. It may also entail conducting a few sample interviews (sometimes with the outreach workers who will be administering the survey) to make sure the questions are understandable, elicit usable answers and use culturally and educationally appropriate language. Any feedback can then be incorporated into the survey before beginning the data collection phase.

Recruit Participants and Collect Data

The next step is recruiting participants and conducting interviews, focus groups or other data collection. During or before this step, several trainings can be set up, including how to administer a survey, protect client confidentiality, store data, and conduct basic data analysis. The collaborative research study should rely on the strengths of all research partners, and those team members who wish to learn new skills should have access to appropriate training.

In our example, the research team suspected that it might be difficult to recruit female clients for the study. They also knew that the interview would be long and detailed, and require that the clients trust the interviewer. They decided to allow extra time for recruitment, and to allot more funds for providing incentives that would attract clients. One of the case manager's daughters was an experienced babysitter, so they provided child care for any client with children. The researcher knew that other projects at the university had a surplus of incentives, and was able to get phone cards to give to participants and cookies to serve during the interview. The outreach workers were eager to conduct the interviews to learn more about their clients as well as to earn extra money. The researcher set up a training on client confidentiality, interview skills and data cleaning for all interviewers.

Often, as is the case in the example above, CBO staff collect data through conducting interviews with clients. However, this changes the role of CBO staff and the dynamic between them and clients. Instead of being a sympathetic ear, they are now asking questions and maintaining appropriate distance from clients so as not to influence responses. Alternatively, staff from the research side of the collaboration may conduct data collection efforts, requiring that strangers come into the service arena asking questions of clients, which also might upset the balance and cause distrust. If clients are getting paid to answer a survey, for example, that can have an impact on the relationship between client and case manager. If a researcher is supervising CBO staff in data collection, it is important to understand roles and negotiate supervision methods. CBO staff may have very different styles of communication and researchers need to follow the appropriate channels of supervision that are built into the CBO. Taking advantage of the different perspectives and experiences of team members in constructing how the data will be collected and determining who does what can lead to insights that would otherwise go unnoticed.

Enter and Clean Data

After the data have been collected, they are usually entered into a computer database. Data cleaning and quality control occur before, during and after data entry. Before data entry, questionnaires should be cleaned, that is, reviewed for responses that don't make sense or are out of range; for example, if someone lists their age as 150. For quality control during data entry, data should

FIELD NOTES

A collaboration between a researcher and an agency targeting underserved communities of color wanted to design a survey that accurately reflected the experiences of the community. However, designing the survey took longer than the researcher expected, and there was disagreement between the researcher and CBO staff on wording.

For example, the researcher developed questions about being hit by family members hard enough to leave a mark or wound. The original question was: "Did you consider that physical abuse? Yes or No." Some of the CBO staff thought it would be better to ask whether the respondent thought of this as "discipline." After a long discussion with different opinions, the question was reworded to ask whether the respondent thought being hit was "physical abuse, discipline, or both."

The revised question generated interesting data that better captured the realities of those being interviewed. The CBO staff's expertise helped shape more accurate survey questions.

be entered into the computer twice, preferably by different people, and compared. This verification assures consistent data entry. After data entry, the file can be re-checked by a computer program for out of range and inconsistent responses. For qualitative data, the equivalent of data entry is transcribing the text of a tape-recorded interview and/or writing up field notes.

Data entry can be a time-consuming task if the research project has reached a large number of clients with a long survey. Data entry can be done by CBO or research staff, or it can be sent to a professional data entry organization or professional transcriber, to which the researcher should have access. If a project is considering conducting many interviews, it might be a good idea to budget for an outside organization to do data entry.

In our example, the CBO had a summer intern whom they recruited to do the data entry. The program manager volunteered to do the data cleaning so that she could read through the interviews and get a sense of what clients were saying. The researcher also participated in some data cleaning and provided quality control of the data entry.

Analyze Data

For quantitative data, the first step is to look at frequencies, that is, the number and percent of people who answered each particular response, for each question or variable. Variables include demographics (e.g., age, race/ethnicity, gender, income, etc.), behaviors (e.g., condom use, accessing needle exchange) and attitudes (e.g., self-esteem, feelings about condoms). Frequencies provide descriptive information about the population, including who attends the programs or the prevalence of certain risk behaviors. After frequencies, certain variables can be chosen for comparison. This allows for analyzing the data by subgroups, such as comparing males and females, different age groups, etc. Comparisons can also be made across time, if longitudinal data is collected. More complicated comparisons can be conducted to determine the relationship between more than two variables. These types of analyses are generally done by the researcher or statistician because they require statistical computer programs such as SAS and SPSS and specific technical expertise. It is important for CBO staff to have access to data and software at all times, especially once the research project has ended. This will help them if they request further analyses or hire their own data analyst later.

For qualitative data, the first step is to read the transcripts and/or field notes. It's a good idea to write down ideas that come to mind while reading the transcripts, including questions, surprises or any common themes that arise between transcripts. If there is a transcript that is radically different from others, it may be worthwhile to spend some time examining how it diverges from the rest of the data and what made it different. Because qualitative data involves words instead of numbers, the raw data in the form of transcripts is often more accessible and understandable than quantitative data. However, it is necessary to develop a data analysis plan, a systematic way of handling the text. Some people who work with a lot of qualitative data prefer to use a computer program specifically designed for this type of data such as NUD-IST, ETHNOGRAPH or ATLAS-TI. All of the text can be put into the program, and then certain text and terms can be flagged or noted.

Another way to manage qualitative data is to summarize each interview into a more manageable form, usually a couple of pages. Researchers and CBO staff can jointly decide

the areas they want to focus on and then summarize those areas of the transcript in 1–4 pages. This way, they can have the data in a more manageable and workable form, instead of working with a 30+ page transcript. Summary sheets can then be used to draw conclusions and refer to the original transcript for key quotes. The process of reading and discussing the interview transcripts and/or field notes can allow for equal participation of all parties. In best practice, both CBO staff and researchers will provide unique perspectives on making sense of the interviews.

In our example, the research team collected both quantitative and qualitative data. Once the quantitative data were entered into the database, the researcher took over, giving it to her statistician to analyze the data and run frequencies. The next collaborative step was to interpret the data. Both researcher and program manager felt good about the data they collected, and had some sense of what they might find out from reading the surveys and doing data cleaning.

For the qualitative data, the research team divided up the transcripts from the interviews among the research and CBO staff and each member was responsible for summarizing the interviews into 2–4 pages. There were six members of the team (researcher and statistician, CBO program manager and three case managers) and each member was given three interviews to summarize. The summaries were all verified by the researcher. Halfway through the process, the CBO's summer intern expressed interest in learning to summarize, and one of the case managers left the agency, so the intern stepped in to the analysis team. The team then met and jointly read through each summary. They created a sheet that listed different types of barriers to HIV testing that clients mentioned, such as childcare, shame, fear, etc., and then summarized the areas where the participant discussed each of these issues. They also started another list of issues that popped up sporadically but were interesting, such as drug users injecting their partners.

Interpret Data

Interpretation gives meaning to the data analysis and allows for drawing conclusions about the participants and/or the program. This is the part of data analysis that incorporates other research and experience into understanding what the data mean. The input of both researchers and community service providers is especially important in this phase as they have different experiences and knowledge that can make the findings clearer. In the interpretation phase, the research team can work with the statistician to look at different aspects of the data, or reinterpret the data using other variables.

In our example, the research team got rich information about their clients and barriers to HIV testing. Through their quantitative data they learned that most clients knew about early intervention and treatment for HIV, and that had no effect on their desire for testing. One case manager suggested they look at whether there was a difference between men and women, or between those who had access to health care and those who didn't. Again, there was no effect. This surprised the program manager and made her take a closer look at other barriers. The qualitative data gave lots of information about clients' lives and barriers to HIV testing as well. One surprising finding was that women who hadn't been tested were very eager to get tested, whereas men preferred not to test. The reasons women gave were more altruistic, like caring for their family and taking responsibility for their own and their partner's health.

BARRIERS TO COLLABORATION

Research collaborations have the potential to use the best skills, experiences, and ideas of all participants. When it comes to data collection and data analysis, however, there are many myths that can become barriers to having everyone participate. One myth is that data collection is something that only researchers can do. CBO participants may think that they don't have the expertise, and full responsibility for the development and implementation of data collection procedures can fall to the researcher. However, CBO staff are also experienced in data collection. Though they may not call it data collection, CBO staff collect all kinds of data on a regular basis in the form of client intake forms, reports, site observations, evaluation forms and outreach notes. These data help the CBO make decisions, develop new programs and generate funding to support services. Also, because the CBO is intimately connected to its population, the staff are typically in an excellent position to provide important information about how to set up and implement the various stages of data collection (e.g., suggesting appropriate wording for constructing questionnaires), or choosing recruitment venues and procedures.

Another barrier to collaboration is that it takes longer to design surveys, collect data and analyze data collaboratively than when it is solely researcher-conducted or CBO-conducted. More time is necessary for training and explanation and working through cross-cultural differences. Each member of the collaborative research project must be committed to the benefits of collaboration, and allow the extra time it requires.

Working together through the various steps to develop and implement data collection and analysis will result in better procedures that deliver more accurate data. Recognizing and tackling the myths each group may have about the other and their own roles will go a long way in improving the quality of the procedures developed.

A large CBO serving gay and bisexual men in San Francisco wanted to find out why gay men were having unprotected sex. They contacted researchers to collaborate with them on the project, and made it clear that they wanted the researchers' best thinking, but it didn't have to meet academic journal publishing standards. The CBO wanted to get results as quickly as possible from the research.

The research team conducted 90 interviews and set up regular meetings for collaborative analysis of the massive amounts of data that were collected. For 5 or 6 months, researchers and CBO prevention staff met for 3-hour lunch meetings every week. All attendees read every 40+ page qualitative interview transcript, and took turns presenting them at the meetings. Researchers and CBO staff discussed and analyzed the findings together during these meetings.

In effect, the researchers were put on a CBO timeline. As a result, they gathered rich data and implemented two interventions based on the findings.

LEADERSHIP

Even though the process of data collection and analysis may be collaborative, it is important to have clear leadership. Clear leadership enables the process to move forward and facilitates timely decision making. The leader may be either the community service provider or the researcher. If the researcher is the leader, they should ensure CBO participation by providing some basic training about research and analysis and drawing out CBO staff's opinions and ideas. If the CBO is leading the effort, CBO involvement may be more organic than if the researcher were the leader. However, training and encouraging CBO staff participation is still useful.

FUNDING

Money can be the driving or limiting force behind a collaboration, especially in the data collection and analysis phase. Collaborative data analysis certainly requires more time than the alternative. Staff need to be compensated for their work in research to allow adequate time for their participation. Researchers need to be funded to train CBO staff to enable their participation in the process. The party that brings the money to the table often has the most say in the process; literally, how everyone will spend their time. Because CBO staff usually know less about data analysis than researchers, they may initially have less input into the process and feel that their voices are not as important. If the CBO staff also brings funding to the project, through their own funding or by seeking additional outside funds, they may feel more entitled to express their opinions and have input into the project. This can be a way of mediating the imbalance of research knowledge in collaborative data analysis and interpretation.

Data collection and analysis gives the answers to the research questions, what you've been anticipating and working towards since you started planning this process. Because all of your research work has led up to these findings, they are very valuable. Jointly conducting data collection and analysis is crucial in making these findings as rich and useful as possible. It's especially important that CBO voices inform the analysis process to connect the data to the community. In the next chapter, you can see how to take these findings from your data analysis and use them to impact your programs or research.

KEY POINTS: DATA COLLECTION AND ANALYSIS

Data collection and analysis start with the design of a research question and don't end until the findings are implemented and disseminated. Some of these lessons learned are similar to what has been presented in other chapters, and they bear repeating. Others are specific to this phase.

- Both quantitative and qualitative data can be successfully collected and analyzed in a research collaboration. Quantitative data require more time spent during the survey design phase, and qualitative data require more time in the analysis phase.
- Clear leadership and clearly defined roles are very important. Each step of data collection requires a specific person to be responsible for carrying out the task, as well as oversight by a leader.
- Everyone in the collaboration should be prepared through extensive training, especially regarding confidentiality, interviewing, and procedures for data collection.
- Researcher and/or CBO staff turnover is almost a given, so it is best if plans are made for orientation and training of new staff.
- Meeting regularly is required. Research and CBO staff must meet regularly during data analysis.
- Allow for adequate time; collaborative data analysis is time intensive — include this in planning and budgeting
- Decide together when to stop. Sometimes you must stop collecting data no matter how far short of your goal you are; other times, a minimum number of interviews may be required no matter how long it takes.

Case Study

WORKING WITH YOUTH IN HIV PREVENTION RESEARCH

by Gary Harper

I have found that working on the formation and maintenance of community-university collaborations is one of the best ways for me to use my talents in the fight against AIDS. I was part of the collaborative research initiative at CAPS as a junior researcher paired with staff from Tri-City Health Center.

Teen outreach workers at Tri-City Health Center.

Our research project looked at suburban street youth and their HIV prevention needs. It was a great experience for me as I saw firsthand the multiple benefits that could be derived from such collaborative efforts for myself, the agency staff and the youth themselves who were involved in the research project.

When I moved from San Francisco to DePaul University in Chicago, I wanted to be able to connect with the HIV prevention community and recreate the positive experience that I had at CAPS. In September 1997, a graduate student and I developed a community-university partnership with Project VIDA, a nonprofit community-based HIV/AIDS service organization, in order to evaluate two of their HIV prevention programs for youth. The collaborative partnership has now expanded to include more students and agency staff members, and we are now working together to evaluate six programs within the agency and to conduct trainings with Latino-focused community agencies throughout the Midwestern U.S.

When the partnership began, it was clear that the Project VIDA team was extremely familiar with the target population and was able to provide us with a profile of the participants that were attending their programs, while we from the DePaul team were knowledgeable in conducting sound evaluation and research. Thus, we were able to educate and train staff members in how to develop and implement appropriate and useful evaluations. We all had a genuine interest in HIV/AIDS prevention among female adolescents and gay/bisexual/questioning young men (the two groups targeted in the initial efforts). This shared sense of direction and commitment helped us to focus on the ultimate outcome, which was to help protect these young people from becoming infected with HIV. Overall,

communication between both teams was essential, especially in the early stages of the collaborative partnership as we worked together and made important decisions as a team so that all members felt they were having significant input into the process.

Participation in this collaboration has allowed me to give my university students the opportunity to learn about HIV prevention and evaluation by actually being involved in "real world" experiences. This was my first university appointment and I did not want to repeat the errors of many professors by talking abstractly about social issues such as HIV and never connecting the information to "hands-on" experiences. Both graduate and undergraduate students have been able to learn firsthand about the realities and challenges of conducting community-based HIV prevention work, as well as how to run an effective process evaluation that assists in the improvement of community-based programs. They have gained great insight into how real life prevention works in a community setting and about the multiple issues that must be addressed when doing such work.

Working with Project VIDA also has helped me to have a more realistic understanding of how cultural and environmental factors have a tremendous influence on young people's ability to protect themselves from HIV infection and other negative health outcomes. I have seen the devastating impact that the lack of culturally appropriate HIV prevention services has had on this community, and recognize the urgent need for the development and expansion of such programs. My participation in the collaborative team also has given me the support to organize and get involved in social action activities in an attempt to address these social issues. Working on this initiative has reaffirmed my belief in the need for more collaborative relationships between CBOs and evaluators/researchers if we are going to move the science and technology of prevention and health promotion ahead to the point where we can positively impact greater numbers of people.

Chapter 6

Incorporating Findings into Research and Service

The only way for a collaborative research project to fail is to pay no attention to the research findings.

Chapter 6

The previous chapters have outlined the nuts and bolts of conducting the collaborative research project, from choosing a research partner to analyzing and interpreting data. Often, once data analysis is completed, funding ends and the research project is considered finished. But findings can't make a difference unless they are applied to service provision and research practices. A key part of a collaborative research project is incorporating and disseminating the findings. You've got the answers to what you wanted to know, now what are you going to do with them?

Let's say the research collaboration has lasted two years. Together, the research team wrote proposals, trained staff and volunteers, trained each other, strategized and finally succeeded in getting participants into the intervention. The team has even cleaned and analyzed data together. So far so good.

But Reckoning Day has arrived, as it always does. The researcher and CBO staff both have so much invested in the project's outcome that they're very nervous when they finally interpret the data. Both are wondering if they're going to have to give up their jobs or if their communities are going to be left with no way to stem the tide of new HIV infections. What do the clients need? Does the program have any effect? Has the research project answered what they wanted to know?

RECKONING DAY FOR THE CBO

The bottom line is that the research results might be difficult to hear. The hardest part of doing research can sometimes be knowing what to do with the findings. The data might suggest a radical shift in programs or understanding of the target population. Individuals resist change, and CBO program staff are no exception. The results may suggest that a program was a smash success and that unsafe sex might be successfully reduced in your community by a large percentage. The results might say that the target audience needs exactly the kind of program the agency had hoped to implement. Or the data may say that a program failed to have any impact on the rate of unsafe sex, or that people want something completely different than what the agency has to offer. However, results are rarely that straightforward.

The good news is: **you can't really lose.** Knowing that the program had a modest impact is still valuable information. If the findings showed that the program isn't as effective as hoped, there are still two options which may serve the community well: changing the program design, or even shutting down the program. If the findings showed that the target audience needs a different kind of intervention, another option is to start a new program.

Starting Programs

In the best of circumstances, programs start up because there is data to demonstrate a need for them. The data might be about the clients' lives; or they might be from a program evaluation

that demonstrates the need for a new intervention. The data might be from qualitative interviews with a number of people who all convey the same concerns.

It may be the case that after working on a collaborative research project to assess client needs, CBO staff and researchers decide to continue the collaboration to jointly develop a new program. This is an excellent way to translate the research findings into services. Researchers in HIV prevention and other areas of public health, such as injury control or anti-smoking efforts, can contribute their expertise and tell you what the scientific literature has shown works to change behavior — and how much change is reasonable to expect. CBO staff can bring knowledge of what has worked on the ground with their clients, as well as what other agencies in the community are doing. This can help ensure the team that it is not redesigning a program that already exists, or one that has been shown to be ineffective. There might be an existing effective intervention model that can be adapted to a particular target population.

A word of caution: simply because the research findings indicate a need does not mean that the agency is the right one to meet that need. For example, the research might show (and it often does) that unless people have basic housing and food, they won't prioritize reducing their HIV risk. If the agency specializes in HIV prevention, they're probably best off providing referrals to housing and food agencies rather than trying to provide those services themselves.

Changing Programs

Changing programs is one of the easiest ways to incorporate research into services, in part because it's the least risky and takes the least amount of time. Often, it is possible to make changes in an intervention quickly and have immediate impact on your services.

Sometimes research findings go against some preconceived notions or intuition. For example, data may show that many men of color do not want separate educational groups but prefer coming to groups with men of all colors. In this case, the agency may need to start offering men of color a choice of single-ethnicity or mixed groups. Or data may show that individuals from different populations take similar amounts of risk but get infected at different rates. The results can now help with re-targeting the services most needed and best designed to meet a population's needs.

Closing Programs

One of the biggest anxieties about conducting research, especially outcome or evaluation research, is that the findings will show an ongoing program to be ineffective. This leads to fears of loss of funding, inability to get new grants, the entire CBO closing and everyone losing their jobs.

Hopefully that won't be the case. By the time preliminary data have shown that a program is not performing as expected, the CBO staff and researcher most likely were already aware of this, which may be why they formulated the research question in the first place. It takes a lot of courage and commitment to admit that services or theories aren't working, but it provides an opportunity to redirect resources to something that will be more effective.

RECKONING DAY FOR THE RESEARCHER

It is not solely up to the CBO to implement collaborative research findings into their agency. There are several ways researchers should use the research findings to affect their research practices and agenda. Below are ways that researchers can learn and improve their work as a result of working collaboratively.

FIELD NOTES

A multi-service CBO serving suburban street youth originally wanted to compare the effectiveness of a same sex versus mixed sex small group session intervention. The results were conclusive: very few youth came to either session.

Instead of seeing this as a failure, the CBO staff and researcher decided to gather data on what exactly this population needed. They studied interviews that had been conducted with the few youth who did show up, and conducted more qualitative interviews with youth on the street.

They found out that youth wanted easily accessible drop-in services and not fixed small group sessions. As a result of their findings, the CBO opened a drop-in center for teens that provides HIV prevention materials as well as referrals to job training and housing, food and clothing.

Study components of successful programs

Positive and negative results may mean different things to researchers and CBOs. Both groups want to benefit affected communities and save lives. A CBO will hopefully take the well-analyzed data, whether the results are positive or negative, and make sound programmatic decisions based on it. It is also important for researchers to think carefully about both positive and negative results. If they're positive, make sure to understand why this particular intervention worked so well. If the project was a success, work with CBO partners to figure out which components of the intervention were the most successful and may merit expanding. Similarly, look carefully at other parts which were probably not necessary and could be eliminated. How can positive results be translated to understand the likely impact of this intervention on the epidemic as a whole? If the intervention relies on a lot of volunteers, and community interest in HIV is waning, could this program realistically be replicated again? Could the program be replicated elsewhere, given the cost?

Incorporate new questions into future surveys

Interpretation of results often hinges on the validity of the survey questionnaire. For example, the survey may have asked how many sexual partners individuals had, but not have a way in the end of finding out what kind of sex they had with different partners, or what they knew about their partners' HIV status. Or the survey may have included a question about family history of drug use and initiation, which the CBO staff suggested and the researcher would never have thought of. Working in collaboration with CBO staff can help researchers increase their knowledge of population needs and refine or create new kinds of questions. Researchers need to be sure to use what they've learned when designing future surveys with this population.

Disseminate findings faster

By now it is obvious that researchers have very different timelines than CBOs. Like CBOs who want multi-year funding because it assures their intervention's funding, researchers also prefer those contracts which assure their own project's financial stability. Researchers may want a year to do formative research, another year to do an intervention, and six months to do analysis and write up and distribute results. Look for ways to share early data quickly, and to draw interim conclusions. CBO staff can help suggest ways to do this through the data cleaning and analysis phases of the research project. This epidemic is still relatively young and changing quickly. A study can grow to be irrelevant if it takes too many years to complete.

Disseminate negative results

Researchers are also nervous about how results come out. Along with hoping the research will benefit the community, they also want to contribute to the scientific literature. For a variety of reasons, however, many researchers don't publish articles when an intervention fails to show effective results. Not publishing articles about ineffective programs does a disservice to those who need to know the outcome of the research project so as to avoid repeating errors. If an academic journal won't accept an article about unsuccessful programs, try to publish the results through conferences or self published reports.

The conclusion of a collaborative research project is not really the end, but rather is part of a cycle. The only way for both researchers and CBOs to really fail is to pay no attention to the research findings. Research can help give the community at risk the services it deserves and needs, and collaborative research is an important tool in achieving that. Feel free to challenge the research, but let it also challenge you.

KEY POINTS: INCORPORATING YOUR FINDINGS

- Research findings are not used to judge goodness or badness of service provision, but to help improve prevention services.
- Findings should inform both the researcher's research direction as well as the CBO's program direction.
- Collaborative research findings can be used to start, modify or close programs.
- Begin discussing potential implications of preliminary findings.
- It is important to publish and disseminate findings about programs or methods that are ineffective.
- Researchers and CBOs together can illuminate the findings through discussion.
- The only way for a collaborative research project to fail is to pay no attention to the research findings.

Chapter 7

Disseminating
What You've Learned

Without dissemination, we're bound to repeat each other's mistakes.

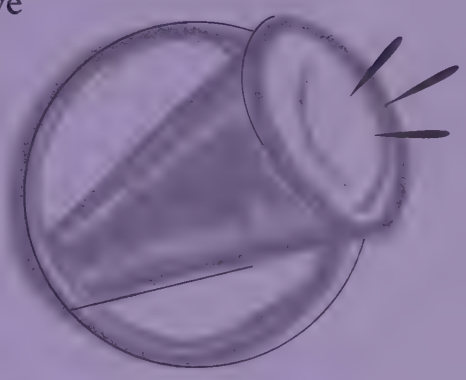
Getting the word out should not be a last minute thought, but an integral part of a research plan.

Chapter 7

Getting the word out about what the collaboration team has accomplished is crucial. CBOs, researchers, funders, health departments and Community Planning Groups are all eager to know more about what is happening and what is making a difference in HIV prevention. Too often, however, dissemination of research findings is considered only after the collaborative research is finished. For CBO staff, this might mean hashing out a report to the funder trying to justify the grant money. To a researcher, this might mean trying to find an extra few months to write and submit a journal article, or giving a formal presentation at a conference.

One simple way to avoid this frustration is to build in a dissemination plan from the beginning of the collaborative project. Along with planning how the research question is formed, who conducts interviews and how the data is analyzed, be sure to plan who you want to reach with your findings, how to reach them, who on your team will write it up and how it gets delivered.

If the research team has followed all the suggestions thus far in the manual, they will be ahead of the game for dissemination because they will have disseminated along the way. Meeting regularly and including a variety of CBO and research staff in meetings is one way to disseminate within the collaborative organizations. When inviting the head of the CBO or the project officer from the funding organization to a meeting, listen to their questions to get an idea of what is important for them to know. In addition to helping formulate the subject of the dissemination plan, this builds an audience for the final product by involving them in the process.



Similarly, disseminate to persons outside of the collaboration as research progresses. For example, as part of the data analysis you might want to hold an informal focus group with clients or community members to see if they agree with the findings. While in data analysis, present findings to other researchers to help focus thoughts and get suggestions for dissemination through journals. Be sure all articles and presentations are peer reviewed by both researchers and CBO staff.

MULTIPLE OUTLETS

Dissemination can take any number of forms, from a conversation with a colleague in the hallway, to an article in an international journal. Different outlets have different audiences, from very specific to broad reaching. Remember that each outlet has a very different timeline, and time your dissemination plan accordingly. Also, the language and content for each can vary widely.

Scientific journal articles — These are submitted and then peer reviewed before publishing. Can take anywhere from 6 months to a year before publication. Audiences are researchers, funders, media.

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Magazine articles — These can be written and submitted or suggested via a query letter. Sometimes the magazine may decide to assign your article suggestion to a staff writer who then interviews you and writes the article. Timeline is 2–6 months. Audience is the general public.

Newsletter articles — Can be an agency newsletter or wider community newsletter. Usually newsletters are eager to receive submissions. Timeline can be fast if newsletter is published monthly. Audience can be very targeted, usually CBOs, funders, activists.

Reports — Self published reports can be mailed or faxed to any number of audiences. Timeline can be fast, depending on when you decide to publish.

Press releases — Should primarily be considered only if the CBO or research institute has a media relations department. Research findings must be new, different and exciting to draw the interest of the press. Should get response within days, if any paper, television or radio station decides to write a story. Audience is the general public.

Briefings — A good method for providing feedback to a targeted audience. Should be done with adequate outreach and groundwork so that you don't throw a party and no one comes. Timeline is 4–6 weeks.

Letters to the editor — This is a good choice for presenting your research while voicing an opinion. Can appear in a few days if accepted. Audience is the general public.

Presentations, workshops at conferences — One of the best ways to present research findings in a personal way. Also provides for instant feedback and discussion. Abstracts for oral presentations or posters are submitted and reviewed for acceptance. Timeline is 4–6 months. Conferences have different audiences, so be sure to choose those that target both researchers and CBOs.

Internet — Posting information on a web site is fast and relatively easy. If you don't have your own site, look to a reputable web page in your field. Timeline is only a few days, but the audience is highly unknown, ranging from highly targeted to very general.

MULTIPLE AUDIENCES

Along with multiple outlets, there are multiple audiences for disseminating information. A dissemination plan should take into account all the different persons who might benefit from hearing about the research project. Collaborative partners should share mailing lists to reach the broadest possible audience.

CBO — Invite not only the director, but the outreach staff and everyone involved in providing services. Outlets: report, briefing, newsletter.

Research institute — Often academic institutes have Brown Bags or other seminars built into their schedules. Outlets: report, briefing, journal article.

Clients — If you've interviewed clients, be sure to let them know what you've learned. Outlets: flyer, newsletter, briefing, Internet.

Other CBOs — Other agencies working with similar populations can benefit from what you've learned. Outlets: report, briefing, newsletter, conference, Internet.

Other researchers — Other scientists will be interested in your findings. Outlets: journal article, conference, Internet, press release.

Community groups — Your research could be of interest to community groups outside of HIV prevention, such as family planning clinics, STD clinics, violence prevention groups, Alcoholics Anonymous or Narcotics Anonymous, boys or girls clubs, etc. Outlets: report, magazine article, newsletter, press release, letter to the editor, Internet.

Department of Public Health and Community Planning Groups — These two groups, who are responsible for many funding decisions, should always receive research summaries. Outlets: report, briefing, journal article, magazine, newsletter, Internet.

Key decision makers — Depending on your study, other influential groups in your community might like to hear about your work: law enforcement officials, school officials, local politicians, etc. Outlets: report, magazine, press release, letter to the editor, Internet.

BRIEFINGS

Briefings are one of the most popular and effective ways of disseminating information. Unless there is a built-in audience (clients at the intervention, agency staff at an in-service, etc.), don't just assume that people will show up. Get the invitation out in time for people to put it on their calendars (2–4 weeks in advance) and follow-up a day or two before to get RSVPs. If a variety of people have been involved from the beginning, they are more likely to want to come to a briefing at the end of the research project.

Here are some tips for planning an interesting and dynamic briefing:

- **Summarize findings.** Break the results down into easily understood categories. Turn each concept into a 3 or 4 word phrase. Leave details to handouts.
- **Find the best presenter.** Presenters should be dynamic and good speakers. Include a mix of CBO staff, outreach workers and researchers.
- **Practice.** Have each presenter practice in front of an audience before the briefing to get feedback and increase confidence.
- **Use visual aids.** Slides, overheads, PowerPoint presentations all break up the talk and give the audience something to focus on.
- **Make it personal.** Whenever possible, include quotes from interviews, personal stories or photos of the intervention. Bring in one of the clients and let them tell their own story. Remember to get written permission before using any photographs of clients and to protect clients' identities in any materials presented.
- **Provide food.** Any enticement will increase the turnout for your presentation. Once people get there, they will be interested to hear what you have to say.

- **Provide written handouts of everything covered.** Every slide and overhead should be copied for handouts. Outlines of each person's talk should also be available to take home. You can provide additional materials that weren't covered as well.
- **Leave time for interaction/questions.** Plan for at least 20 minutes of questions at the end of the briefing. This is the time for you to hear reactions and clarify anything that might have been omitted.
- **Give contact information.** Include contact information on all handouts. Bring lots of business cards if you have them. Be sure to include name, address, phone, fax, e-mail and Internet site.

Adapted from *Making a Difference to Policies and Programs: A Guide for Researchers*.

Without dissemination, we're bound to repeat each other's mistakes. Getting the word out should not be a last minute thought, but an integral part of a research plan.

KEY POINTS: DISSEMINATING WHAT YOU'VE LEARNED

All of the dissemination strategies listed above can be done collaboratively. Although you may not want to do every single dissemination activity together, CBO staff and researchers should decide together who does what. To make the process truly collaborative, here are some suggestions:

- When giving briefings, have both researcher and CBO staff present. It is especially important to invite the CBO staff to present at the research institution. Likewise, researchers should present along with the CBO staff at agencies.
- For published materials, include CBO staff name on journal articles, researcher name in newsletter articles. Allow CBO or researcher partner to have significant input into the articles.
- Apply for a presentation or workshop at a conference and give it together. Researchers should invite CBO staff to present with them at traditionally research-oriented conferences. CBO staff should encourage researchers to present at traditionally service-oriented conferences.
- Help recruit the audience for briefings. Use combined professional networks to get the word out. Share mail, e-mail and phone lists whenever feasible.
- Train each other. If CBO folk have never written journal articles, take the time to give them examples to read and guidelines on what to expect. Likewise, if a researcher has never presented to an audience of service providers, brief them on what to expect and help shape the presentation.
- Include CBO staff as peer reviewers for research articles, grant proposals and presentations.

Case Study

NEW CONSERVATORY THEATER CENTER

by Lisa Heft

New Conservatory Theatre Center is an agency that develops interactive theatre-in-education touring programs on social issues for young people. We decided to evaluate the effectiveness of one of its HIV/AIDS plays for high school youth as a means for increasing parent-adolescent communication on the subject.

FLEXIBLE TIME

Luckily the funding covered a half-time position for me. I cannot imagine adding this research project to an existing workload without full agency support and their realization that this would be a time-intensive project. When things were slow I was able to do some grant writing for the agency. During busier phases in the research project I was on the road conducting research or sitting in a little room for hours counting, cleaning and sorting completed surveys preparing them for data entry.

AN ARRANGED MARRIAGE, BUT A GOOD ONE

I had the wonderful good fortune to be matched with Tom Hall, a researcher whose style fit mine, who had an interest in theatre, and who treated me as a fellow expert and colleague.

AWASH IN A SEA OF PAPER

I had a tiny office with a desk and a phone to do my work, and if you were to look in the door you would maybe find my little face peeking out amidst the towers of 21 stacked boxes and two file cabinets full of surveys. During one particularly rainy season our basement offices flooded from the street above — if you were to look in the door at that time you would have seen my little face poking out between towers of waterproof tarps.

ONE DAY MY JOB CHANGED

At one point I had to take a full-time job at another agency. What would happen with my research project? Would this be the obstacle that prevented its success? I made a

Teen actors in a New Conservatory Theater Center production at a high school.

deal with my new workplace and was able to move my project there, working on it after hours. Tom coming to my worksite gave the project credibility with my new supervisors.

IT WANTS MONEY

We had to do an unforeseen mailing of over 3,000 consent forms. I had to hire a temporary worker to help count and code the forms with me during a time when I was needed in my day job. Once I had to pay someone to drive the surveys up to the study community. When my abstract was accepted at a conference I had to print up a billboard-sized poster to explain the research. Little money surprises throughout. Fortunately the funder was involved and flexible and supported these additional costs.

WHAT IF NOBODY COMES?

Our hypothesis was that giving the same dramatic intervention to parents and their teenagers would increase intergenerational communication on HIV/AIDS. But so few parents *came* to the performances that we did not have enough to even *study*. That might have been the demise of the whole project. Luckily, though, we included an optional essay question: "Do you have anything to say about increasing parent-teen communication about HIV/AIDS?" And though young people may *seem* to be apathetic at best about information coming from their parents, we received over 1,200 responses overwhelmingly asking us to help parents talk *more* with their kids. So we clustered, coded and counted the responses and the wealth of information this represented was so rich we are still using it years later. And the fact that nobody showed up for the parent performances was in itself useful and concrete data.

HOW DID IT ALL TURN OUT?

With help from the collaborators I was able to conduct the research and write a paper. It was posted on the research agency's web site, and they helped me submit it to the International AIDS Conference, where it was accepted for a poster presentation. My researchers and funders found extra money to send me to my first conference ever! I also presented the findings locally to other scientists and community researchers in briefing sessions and at a national conference. And I was invited to help write an internationally distributed fact sheet on parent-teen communication.

It was hard work, but my scientist and funder partners kept me inspired and headed in the right direction. The experience was marvelous, and I learned many things — from evaluation methods to writing research papers to how to present at a conference.

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Appendix B *The CAPS/NCG Collaborative Research Consortium Model*

CAPS has developed and evaluated a successful model for research consortia that has been replicated across the country. The following were the key components of the model:

- A consortium of 11 CBOs, matched researchers, 2 statisticians, a program manager, and administrative support staff
- 10–20% of a CAPS researcher's time per research project, with an additional dedicated statistician for each team
- Up to $50,000 in intervention and $10,000 evaluation funding per year for each CBO
- An initial 4-day workshop which provided CBO participants extensive training in research design, data collection and analysis and allowed the research/CBO teams an opportunity to begin crafting their project
- Monthly meetings where participants received additional training, collective problem solving and support
- A working partnership with local corporate and private philanthropic funders (Northern California Grantmakers — AIDS Task Force) who actively participated in monthly meetings and problem-solving
- A program manager to support the scientist-CBO pairs, facilitate training and assistance and remove obstacles to research project implementation
- Ongoing technical assistance, including scientist and statistical consultation, data entry and statistical analysis
- Additional funding to disseminate findings to colleagues and community members

THE MODEL:

- The project was initiated by a Request for Proposals (RFP) issued by the funder.
- After the agencies were selected, the University hosted an intensive workshop course on the basics of research and evaluation. The workshop was conducted over four consecutive weeks, for a total of 32 hours of instruction. Topics included protocol design sample selection, instrument development, staff training, research implementation, and data cleaning and analysis. The small group format provided the CBO staff the opportunity to develop peer support for the learning they were doing.
- Following the workshop, CBOs were each paired with a CAPS researcher based on common expertise in population, the needs of the research or proximity. Each team negotiated the final details of the research question. They also negotiated their respective roles and a schedule for staying in contact. These varied according to the needs of the participants, but an initial meeting at the CBO to meet the CBO staff was standard across all projects.
- The entire group (CBO staff, researchers, funders and consortium management and support) met for a two-hour lunch meeting monthly for updates and training.
- Researchers and CBOs jointly developed the research instruments, researchers completed the Committee on Human Research (CHR) applications, and CBOs were responsible for data collection. Researchers participated in quality control of data collection, and several participated in staff training at the CBO, as well. Data analysis was conducted jointly, as was the dissemination.

We recognize that this fairly resource-intensive, "Cadillac" version of collaborative research will not be accessible, available, or even appropriate for everyone in all situations. The added value of the consortium was significant.

- Projects were able to learn from each other.
- CBOs were able to teach, learn and get support from other CBOs also trying to negotiate relationships with researchers.
- Academic researchers also got to teach, learn and get support from other researchers about negotiating relationships with CBOs and conducting community-based studies.
- Because the group met monthly, the consortium provided a convenient, regular means for additional training.
- Program manager and funder were able to track progress and problems in multiple collaborative projects and intervene with assistance when warranted.

Appendix C Finding Collaborative Research Partners

GRADUATE SCHOOLS OF PUBLIC HEALTH, PSYCHOLOGY, ETC. (finding researchers)

Most Master's programs for health-related subjects require students to work in a service organization as part of their studies. This is a great way to get a junior researcher for free. It's also a good way to start a relationship with a researcher who is just starting out, and will hopefully continue the process of collaborative work in the future. Junior researchers may be more likely to work within the service organization, spending time at the agency to see how services work.

Graduate student researchers may have limited time and expertise, so be sure to keep realistic expectations for the collaboration. For example, a graduate student researcher may not have expert SPSS skills, so they may need to work with an advisor to conduct a detailed data analysis.

The Association of Schools of Public Health lists all the accredited schools on its web page: http://www.asph.org/aa_section.cfm/151.

STATE AND LOCAL HEALTH DEPARTMENTS (finding researchers and service providers)

All service agencies that are funded by state or local health departments are entitled to technical assistance (TA). Many researchers at health departments are already collaborating with service agencies. Also, researchers at health departments are familiar with service agencies and can help outside researchers hook up with agencies that may need their services. Collaborations with health departments are likely to be more long-term, as the relationship will continue through funding and other sources.

The NASTAD web site has a list of names and contacts for state health departments: http://nastad.vertex.net/res_state_directory.asp?menu=res.

CDC (finding researchers and service providers)

Again, agencies that are funded by the CDC are entitled to TA, including capacity building and evaluation. Contact your program officer for more information. The CDC's National Prevention Information Network (NPIN) maintains a searchable database of agencies working in HIV prevention. Researchers can find agencies working in their community by calling the hotline (800-458-5231, 800-243-7012 TTY) or going on-line: http://www.cdcnpin.org/db/public/rsmain.htm.

BEHAVIORAL AND SOCIAL SCIENCE VOLUNTEER PROGRAM (BSSVP) (finding researchers and service providers)

The American Psychological Association, Office on AIDS established the BSSVP to help researchers on the local level get involved with community-based service agencies. The BSSVP links researchers and service providers for collaborations. The researchers are volunteers, and the program trains researchers on collaborative work, making them more likely to be prepared for the special needs of collaboration.

Contact: E. Duane Wilkerson, M.P.H., Program Director
(877) 754-1404
DWilkerson10@home.com

Contact: Robin Kelley, Program Coordinator
RKelley@apa.org

Appendix D *Glossary of Research Terms*

CLOSED-ENDED QUESTIONS: Questions in an interview or survey format that provide a limited set of predefined responses.

COMPARISON GROUP: A group of individuals who have similar characteristics to the program participants (such as race/ethnicity, gender and age) which is compared to the program (or intervention) group in an evaluation process to determine which type of services, activities or products provided by your program produced the expected changes. The comparison group may not receive any services or may receive a different set of services, activities or products.

CASE STUDY: A non-experimental design that provides a detailed analysis of an individual program. The focus is on description of activities, not on determining cause. Case studies may be performed on several programs simultaneously to allow qualitative comparisons of certain aspects of the programs.

COHORT STUDY: See Longitudinal Study.

CONTROL GROUP: A group of individuals whose characteristics (such as race/ethnicity, gender and age) are similar to the program/intervention participants but do not receive the program or intervention evaluated. This is similar to a comparison group, except that participants are randomly assigned either to the intervention group or the control group. A control group is used to assess the effect of your program on participants as compared to similar individuals not receiving the programs or activities evaluated. The same information is collected for people in the control group as in the experimental group.

CORRELATION: A statistical measure of the degree of relationship or association between variables.

CROSS-SECTIONAL STUDY: A cross-section is a sample of a population. A cross-sectional study examines this sample at one point in time. Successive cross-sectional studies can be used as a substitute for a longitudinal study.

DATA: Specific information or facts that are collected. Variables can be demographic, behavioral, descriptive, etc.

DATA ANALYSIS: The process of systematically applying certain techniques (e.g., statistics) to describe, summarize and compare the data collected.

FORMATIVE EVALUATION: Evaluation during the design and pre-testing of programs to guide program development. Used to assist planners, managers and staff to develop a new program or improve an ongoing program.

IMPACT EVALUATION: The assessment of the effects of an intervention beyond the outcomes on individuals targeted by the intervention, i.e., what is the impact of the availability of the program on the broader community?

INCIDENCE: The number of new cases of a disease that occurs in a specified population during a specified time period.

INTERVENTION: A specific activity or set of related activities intended to bring about HIV risk reduction in a particular target population using a common strategy. An intervention has distinct process and outcome objectives and a protocol outlining the steps for implementation.

LONGITUDINAL STUDY (also called COHORT STUDY): A study in which the same persons are observed repeatedly over time, usually at regular intervals.

NEEDS ASSESSMENT: The process of obtaining and analyzing information from a variety of sources in order to determine the needs of a particular client, population or community.

OPEN-ENDED QUESTIONS: Questions in an interview or survey that allow the respondents to provide their own answers, as opposed to having to select one of a limited set of predefined responses.

OUTCOME EVALUATION: The process of determining the degree to which a program or intervention achieves the intended objectives. Outcome evaluation is concerned with detecting any changes as a result of the intervention, and the degree to which they are the result of the intervention.

OUTCOME OBJECTIVES: The overall intended effects of the intervention, specifying its purpose and mission. These might include increased knowledge about HIV, changing risk-related behaviors, promoting community norms for safer sex or reducing HIV transmission.

PILOT TEST: A trial run with a few participants to assess the appropriateness and feasibility of the intervention procedures and data collection instruments such as questionnaires.

PRE AND POST DESIGN: An evaluation design in which a single program or group is measured prior to program implementation and again after the end of the program.

PROCESS EVALUATION: A descriptive assessment of the implementation of program activities, what was done, to whom, how, when and where, to learn how the program was implemented and if it reached its intended audience.

PROCESS OBJECTIVES: These describe the specific intervention activities, what is needed to carry them out, the people responsible for carrying them out, and when they will be completed.

QUALITATIVE DATA: Data that is in narrative or text form, for example, information collected from focus groups or in-depth interviews.

QUANTITATIVE DATA: Data that is numerical, in the form of numbers, for example, survey data and data from epidemiological reports.

RANDOM ASSIGNMENT (or RANDOMIZATION): A method of assigning research participants to two or more groups by chance. Randomization is done to draw samples that are representative of a known population and to ensure that groups can be statistically compared.

RANDOM SAMPLING: A technique where each research participant is chosen entirely by chance and each member of the population has an equal chance of being selected for the sample.

RELIABILITY: The consistency of a measure or a question in obtaining very similar or identical results when used repeatedly.

REPRESENTATIVE: Indicates that a sample is similar to the population from which it was drawn and, therefore, can be used to draw conclusions about that population.

RESEARCH DESIGN: A plan that defines the number and type of variables to be studied and assesses their relationship to one another using well-developed principles of scientific inquiry.

SAMPLE: A group of participants selected from a total population with the expectation that studying the group will provide important information about the total population.

STATISTICAL SIGNIFICANCE: A measure of whether an observed difference or relationship is larger or smaller than would be expected to occur by chance alone. Statistical results are often considered to be significant if there is less than a 5% chance (.05 or 5 out of 100) that they would have occurred by chance alone.

TARGET POPULATIONS: Groups of people who are to be reached through the intervention.

VALIDITY: The extent to which a survey question or other measurement instrument actually measures what it is supposed to measure.

VARIABLE: A characteristic that can change or vary among different people or in the same person over time. For example, race or ethnicity varies among individuals, and income varies for the same individual over time.

Adapted from *Evaluating CDC-Funded Health Department HIV Prevention Programs, Glossary of Terms*
http://www.cdc.gov/hiv/aboutdhap/perb/TERMSfinal.pdf

Appendix E Other Manuals

Good Questions/Better Answers: A Formative Research Handbook for California HIV Prevention Programs
Center for AIDS Prevention Studies
http://www.caps.ucsf.edu/goodquestions/

A Bridge Between Communities (videotape)
The Detroit Community-Academic Urban Research Center
University of Michigan School of Public Health
Phone (734) 764-5171
rojmcg@umich.edu

Getting Started: The NMHA Guide to Establishing Community-Based PreventionPrograms
National Mental Health Association
1021 Prince Street
Alexandria, VA 22314-2971
Phone (703) 684-7722
Fax (703) 684-5968

The Program Development Puzzle: How to Make the Pieces Fit
National Minority AIDS Council
http://www.nmac.org/NewsLetters/NMAC/Technical/puzzle.pdf

Community-Based AIDS Prevention and Care in Africa: Building on Local Initiatives
Population Council
http://www.popcouncil.org/ebert/wellbriefing.html

Knowledge from Action: Community-Based Research in Canada's HIV Strategy
Canadian HIV/AIDS Clearinghouse
Canadian Public Health Association
1565 Carling Avenue, Suite 400
Ottawa, Ontario, Canada K1Z 8R1
Phone (613) 725-3434
Fax (613) 725-1205
aidssida@cpha.ca

Making a Difference to Policies and Programs: A Guide for Researchers
The United States Agency for International Development
Health and Human Resources Analysis for Africa
http://www.usaid.gov/regions/afr/hhraa/guide/eng_intro.htm

The California Wellness Foundation: Reflections on Capacity Building
California Wellness Foundation
http://www.tcwf.org/reflections/2001/april/index.htm

Beyond Our Borders: A Guide to Twinning for HIV/AIDS Organizations
Interagency Coalition on AIDS and Development
http://www.twinningforaids.com/

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www.caps.ucsf.edu/collaboration